A GUIDE *for the* CAREGIVER

Promoting Older Manitobans

Manitoba
Building for the Future

Acknowledgements

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INTRODUCTION

In Canada today there are 4.5 million caregivers. People caring for their loved ones are strong and courageous individuals who play an important and invaluable role in our society. Most people who require care wish to remain living in their family homes and familiar communities for as long as possible. This can often be achieved with the assistance of caregivers. A large percentage of these caregivers are relatives or friends.

Caregiving can be both rewarding and challenging. Caregivers may feel a sense of accomplishment and satisfaction at being able to look after a loved one. They may appreciate being able to reciprocate their love and strengthen their bonds with family members. However, they may also be juggling the needs of other family members and personal commitments and may feel ill-equipped to handle the physical and emotional demands that accompany the caregiver role.

INTRODUCTION

This guide discusses some of the rewards and challenges associated with caring for an older adult, and various ways to meet and overcome common challenges. The information contained in this publication will help you become more comfortable in your caregiving role and better able to manage the responsibilities and demands.

CAREGIVING – *A NEW EXPERIENCE*

Those caring for an older individual often realize that coping with the changes means moving through the experience and looking ahead. It is important to establish a relationship that is comfortable for the person you are caring for and yourself.

Focus on what the person can do – respect his/her desire to remain independent.

Learning how to accept help is central to self-care for everyone. However, receiving help from others is difficult, especially for an individual who has not needed it before. Sometimes the wish to maintain or regain control can result in some challenging behaviour causing difficulties for the caregivers. While the behaviour can be upsetting, it may be better understood if viewed as the senior's attempts to cope with new circumstances. Help the older individual maintain whatever level of independence is possible.

CAREGIVING – A NEW EXPERIENCE

"Thou shalt not parent thy parent."

There is a myth that children and parents reverse roles when the adult child is required to meet the needs of an aging parent. This is not true. Caregivers who recognize that their parents are NOT children are better prepared to care for an increasingly dependent person. Avoiding the tendency to treat older people as children – either through actions or tone of voice – will help them maintain a sense of dignity. Ensuring dignity and privacy will encourage independence.

See the new roles as a change rather than a reversal.

CAREGIVING – *A NEW EXPERIENCE*

IT'S OK TO FEEL THIS WAY.

Any person caring for an older individual is likely to undergo a wide range of emotions. Along with the positive, life-affirming feelings, it is common to undergo disturbing or disruptive thoughts and emotions that challenge your effectiveness as a caregiver. Recognizing that you are not alone in experiencing very powerful emotions at this time can be of great help.

"Why do I feel so guilty? I'm doing the best I can."

Almost everyone in a caregiving role occasionally experiences feelings of guilt – guilt over not doing enough, or not making the best choices. Do not let guilt overwhelm you. It can seriously harm you as a caregiver. Keep your perspective. As well, getting assistance can help minimize feelings of guilt, so maximize your support network.

CAREGIVING – *A NEW EXPERIENCE*

"I am feeling angry and frustrated."

Feelings of anger and frustration are common in a caregiving situation. You may be angry about the changing relationship and your new role as caregiver, or frustrated at your inability to meet all the needs of the older individual. However, taking out your frustration on others only adds to your feelings of guilt and loss of control, and increases the tension between you and others.

If you find yourself snapping at the person you are caring for, stop and take a break. Do something positive for yourself to reduce the tension.

CAREGIVING – *A NEW EXPERIENCE*

"I feel very depressed... what can I do?"

Family caregivers often overlook the fact that they may feel grief at the losses suffered by the aging person, the family and the caregivers themselves. It's important to take regular breaks and maintain interests you enjoy outside of the caregiving role. Build a support network and take advantage of counselling programs offered in your community. All these things will help you manage your caregiving responsibilities.

CAREGIVING – A NEW EXPERIENCE

RESPONSES TO PHYSICAL/MENTAL CHANGES

"I love my mother but I find it hard to accept the physical changes she's undergoing and to see her slowing down mentally. Is it normal to feel upset because I don't like to see her becoming so dependent?"

Yes, it is normal to feel upset over these changes. But keep in mind that we all experience physical changes as we age. We may also experience mental changes. Some changes are reversible, others are not. Regular medical check-ups improve the success rate for changes that may be reversible.

"I am caring for someone who refuses to consider any of my suggestions. What can I do?"

Sometimes those receiving care don't like to accept help and prefer to assert their options. Listening to them may improve their outlook and your understanding of the situation. It may help you develop new approaches and solutions. An honest conversation can help relieve tension, resolve problems and unburden feelings.

CAREGIVING – *A NEW EXPERIENCE*

At the same time, challenging behaviour may also be a sign of an age-related disease, such as dementia. In this case, it is important to learn about the disease and stay informed about common behavioural symptoms. The more you understand about the medical condition, the more confident you will be providing care.

"We've been told that my husband has age-related dementia. He's forgetful and his personality has changed. How can I cope with the changes in his behaviour that I find so irritating?"

Caring for a family member suffering from this kind of chronic confusion can be particularly heartbreaking and stressful. If we are aware of some of the behavioural changes that are associated with dementia we can often cope more easily.

CAREGIVING – A NEW EXPERIENCE

These changes may include:

- repeating questions and conversations
- losing and hiding things
- belligerence or unwillingness to co-operate
- pacing back and forth
- aimless wandering, even wandering outside
- following, or hovering close to others
- yelling, swearing, frowning or scowling
- starting something (for example, getting dressed) and not finishing
- complaining about everything
- retelling stories from the past over and over

It's important to remember that these behaviours are all part of the disease and are just as upsetting to the aging individual as to you. Find out all you can about dementia from the various sources in your community. The more you know about it and what to expect, the less stressful it will be for you to cope from day-to-day.

CAREGIVING – A NEW EXPERIENCE

IS THE EXPERIENCE OF CAREGIVING A NEGATIVE ONE?

No! Caregiving often has positive benefits, such as improved relationships, satisfaction from doing a job well, fulfilling a duty or obligation to your loved one, enhanced knowledge of another, or heightened sense of value and self esteem, may result. Caregiving in some cases may offer a purpose and compensation for lost careers or losses of loved ones.

WHAT ARE SOME OF THE REWARDS AND JOYS OF CAREGIVING?

- a new relationship with person being cared for
- a chance to give back
- a sense of accomplishment
- development of new skills, knowledge, i.e. advocacy abilities
- increased compassion, growth
- new relationships with others through support groups
- creating memories
- less grief for what used to be
- new found joy in the present

PRACTICAL ADVICE – *FOR CAREGIVERS*

Caregiving is reciprocal. Caregivers often receive a great deal from the older person they are caring for -

- Become informed about the physical and behavioural changes of normal aging and those that are disease-related. (For example, normal aging does not cause dementia.) Collecting information from health care services and professionals will help you assess the nature and severity of the changes you notice.
- Get books and tapes from your local library. There is a wide range of material on helpful topics such as stress management and reduction, self-care, spiritual nurturing, etc.
- Look into acquiring equipment designed to make life easier for seniors. Many of these can be borrowed or rented. Some devices, like bathtub aids, can be extremely helpful.
- Stick to a routine when caring for an older person. It provides a sense of security for the individual.
- It is important to plan for the future. Consider your financial situation, your emotional resource and the resources available in your community.
- Be realistic. Ask for help, when you need it, from family, health care providers and professionals.

PRACTICAL ADVICE – *FOR CAREGIVERS*

YOU DON'T HAVE TO BE ALL THINGS TO ALL PEOPLE.

Strive for balance in life, not perfection. Caring for another is an emotional experience for everyone and it can be difficult to find solutions that make everyone happy. The following suggestions can help you cope more effectively with the challenges involved in caregiving:

- Accept that there are some things you cannot change – focus on the things you can.
- Keep a record of major behaviour changes and your responses to them.
- Help the person you are caring for cope with his or her feelings.
- Use various communication techniques, such as touching, hugging, humming and singing. Things like serving a favourite food or taking walks together can help strengthen your relationship with the older person in your care.
- Use humour when handling difficult situations.
- Take time to reflect on success and don't dwell on what you view as failure. Make a point of noting the positives each day.

PRACTICAL ADVICE – *FOR CAREGIVERS*

GETTING THE FAMILY INVOLVED

Keep in mind that each family member is an individual and that your family is unique in its structure. Designing a support plan in advance, with input from all family members, has many advantages.

If something happens, each family member has the satisfaction of knowing that a system is in place that outlines what needs to be done and who will do it. You may find family relationships strengthened as you work together to find creative ways of solving problems.

Finding ways to share caregiving responsibilities helps to keep the situation – and ourselves – in balance.

PRACTICAL ADVICE – *FOR CAREGIVERS*

Here are some tips for planning with your family:

- If your older family member is mentally alert, determine his or her wishes about the need for help and plans for the future.
- Consider the larger network that already exists for you, such as friends, neighbours and in-laws.
- Listen to each other and come to mutual agreement on plans for your older family member.
- Ensure that your plans are feasible and can be put into effect.
- If you reach a deadlock, don't give up. Focus on what's best for the older person. This should get you back on track.
- Try to establish a clear back-up plan for when you can't be available.
- Get as much help as you can from friends and support group members (make sure they fully understand the challenges involved).
- Don't demand too many changes from family members but accept the help they offer and realize that they may want to do it their way.
- Everyone should accept a compromise once all options are explored.

PRACTICAL ADVICE – *FOR CAREGIVERS*

DEALING WITH STRESS

To care for others, first be a friend to yourself. It is critical to remember to take care of yourself. To avoid the stress of caregiving at all times, you need to find ways of managing your own stress. There are no by-the-book rules on how to do this, but the following tips may be helpful.

- Take care of your health. Make sure you get adequate rest, good nutrition and sufficient exercise.
- Trust and accept your own abilities and talents.
- Practise gentleness with yourself and others.
- Be proactive – not reactive. Act in ways that are consistent with your personal beliefs, not in response to the influence of others.
- Remember that anger and resentment are often symptoms of exhaustion.
- Think of resting as recharging, not as being lazy. Let go of petty grievances and big grudges.
- Maintain hobbies and interests you enjoy.
- Recognize and respect your limits as a caregiver. When you reach your limits, look to family, friends, health care professionals and the community for support.

PRACTICAL ADVICE – *FOR CAREGIVERS*

PREVENTING BURNOUT

Continuous feelings of rage, alienation and fear are not normal. Caring for another person, especially over a long period of time, can be physically and emotionally draining. You may find yourself being forced to do routine tasks and wishing you were some place else.
If this sounds familiar, you may be reaching the burnout stage.

PRACTICAL ADVICE – *FOR CAREGIVERS*

Here are some strategies for coping with potential burnout:

- Learn to recognize the signs of stress.
- Find someone you can talk to about your feelings.
- Set realistic goals – determine your priorities.
- Balance work, family and time for yourself. It's critical to make time for you, even if it's just an hour or two.
- Consider joining a support group that can help you manage stress, locate resources and reduce feelings of isolation.
- Talk to a professional, such as a social worker, psychologist or nurse, who is trained in counselling on caregiving issues.
- Check out options available to you through your employee assistance program.
- Take advantage of respite care, which provides temporary caregiving while you take a break.

PRACTICAL ADVICE – *FOR CAREGIVERS*

CAREGIVERS WHO ARE EMPLOYED

Balancing work and caregiving responsibilities is a challenge. Canada's workforce has undergone dramatic changes in the past four decades. As a result, more workers find themselves also caring for aging relatives. A large percentage of these employees are facing high stress levels associated with the constant juggling of work and family.

The good news is, employers are becoming increasingly aware of this trend. They realize the struggle to balance work and family commitments has important implications for employee productivity and, by extension, the health of the organization.

As a result, workplaces are promoting more family-friendly organizational policies, such as flexible work arrangements, family leave, employee assistance programs and educational opportunities.

If you are having difficulties balancing work and caregiving responsibilities, check with your employer to see what help may be available to you through the organization.

PRACTICAL ADVICE – *FOR CAREGIVERS*

ELDER ABUSE OR NEGLECT

The stress of long-term care of an older person sometimes leads to abuse or neglect. This can happen when providing care has become more than the caregiver can handle and he or she will not seek help.

Elder abuse is any action or inaction that jeopardizes the health or well-being of an older person. Sometimes older people are abused by family members, but seniors can also be abused by health care and social service providers, either in the community or in long-term care facilities. Stress-reducing interventions, such as home care assistance and respite care, can help to reduce the risk of abuse.

SENIORS ABUSE LINE

The Manitoba Seniors and Healthy Aging Secretariat has a Seniors Abuse Line, which is a confidential information service. It provides seniors, family members, service providers and the community, access to information on elder abuse (includes existing resources and support services throughout Manitoba) and assistance in accessing those resources.

An elder abuse consultant is available to provide education and training, and to assist communities in co-ordinating services for abused seniors.

Seniors Abuse Line:

in Winnipeg 945-1884

toll-free 1-888-896-7183

For more information you can also check the Manitoba Seniors and Healthy Aging Secretariat web site at www.gov.mb.ca/sd

BUILDING A SUPPORT NETWORK

"My time for keeping up with social contacts is limited. Friends and neighbours have asked that I let them know if there is anything they can do. How can they be included without my imposing on them?"

Being a responsible caregiver includes knowing when and where to get help. Here are some simple tips for asking friends/others for help:

- Keep a list of specific chores or requests.
- Ask your friends what they would like to do.
- Express your appreciation for help given.
- Ask close friends their opinions on how the situation is going; be prepared to hear the truth.
- The company of good friends can be a tremendous morale booster.

ASK FOR HELP

We are often easier on friends or others, than we are on ourselves. Try to remember that no one is perfect. When you look back on actions and decisions that you believe were not the correct choices, recognize that you did not know then what you know now.

BUILDING A SUPPORT NETWORK

SUPPORT GROUPS CAN HELP

There are support groups sponsored by agencies that represent the disease or condition affecting the care recipient (ex: Alzheimer Society, Heart & Stroke Foundation). Other groups are designed specifically for caregivers of older people and may be sponsored by community organizations.

Some groups meet regularly and some meet for a limited number of sessions, usually covering a specific topic at each session. You will probably have to make some inquiries to locate the group that best meets your needs.

Joining a support group offers caregivers an opportunity to:

- share experiences in coping with caregiving responsibilities
- exchange pertinent information, such as the difference between normal aging and age-related illness
- share thoughts and ideas without fear of judgement
- overcome feelings of isolation and helplessness
- exchange practical ideas with other caregivers and explore new ways to solve problems

BUILDING A SUPPORT NETWORK

- share experiences in dealing with the medical community and other professionals
- cultivate gentleness and humour in relationships with others

SEEKING COUNSELLING AND SUPPORT SERVICES

If you wish to locate a support group or some professional counselling, see:

Manitoba Seniors' Guide:
in Winnipeg 945-6565
Toll-free 1-800-665-6565 or

CONTACT Community Information
in Winnipeg 287-8827

Ask about listings under self-help groups/support groups, counselling, seniors, family life or family life education centres.

Outside Winnipeg, refer to the ***Seniors' Guide Toll-free 1-800-665-6565*** or your Regional Health Authority.

As well, ask trusted friends and professionals for referrals.

BUILDING A SUPPORT NETWORK

WORKING WITH COMMUNITY RESOURCES

Becoming more realistic about your caregiving responsibilities includes learning to work with community resources. Although this does take some effort and planning, shared responsibility for continuing care can help you better handle your long-term commitments.

The Support Services to Seniors program includes Community Resource Councils. Many communities have established Community Resource Councils (CRC) to help seniors live independently as long as possible.

For more information about the CRC nearest you, call the Seniors Information Line - Winnipeg 945-6565 or Toll-free 1-800-665-6565.

Be realistic about your strengths and needs.

- Write down what kind of help you need before approaching community resources for assistance.

BUILDING A SUPPORT NETWORK

- Recognize and respect your limits as a caregiver.
- Be realistic about the contributions of family and friends.

BE REALISTIC

Be realistic about the older person's abilities.

- Review what the aging individual can do independently, even with a struggle. The goal is to maintain whatever level of independence is possible.
- If the person in your care is competent, discuss the option of granting a Power of Attorney (POA). Ensure the Enduring Clause is included before the POA is granted.
- Part of the responsibility of caregiving is to protect dependent elders from harm. If you have concerns about the competency of a family member, consult his or her doctor, and then a lawyer, about procedures.

Caregiving services that may be needed include: meal services, housekeeping, private health care, safety services, personal emergency response systems, transportation services and medication information.

BUILDING A SUPPORT NETWORK

WORKING WITH HEALTH CARE SERVICES

Manitoba has a provincial home care program to help older adults remain in their homes as long as possible. The home care program includes family relief, homemaker services, respite care, adult day care and medical and personal care services. When using these services, it is important to develop a working relationship with your case co-ordinator.

Day Hospitals offer assessment and geriatric rehabilitation. They require a referral from the family doctor. If the aging individual in your care is attending a day hospital, consider the day hospital staff as an extension of the care team.

Day programs offer more long-term socialization, and require a referral from a Home Care Case Coordinator.

If private care is an option you wish to consider, consult the yellow pages of your Manitoba phone book under Home Health Services, Homemakers and/or Nurses.

HOSPITALIZATION

When an individual is hospitalized, it is often a stressful time for everyone involved. Here are some tips for getting through the experience with minimal distress.

- Get the name of the head nurse, or primary care nurse, in case you want to discuss a problem, get information or seek a referral.
- The hospital social worker can provide counselling and support and may also be involved in the discharge planning.
- Rehabilitation services work on referrals from the doctor. You should be aware of what the rehabilitation therapy involves and how you can assist the patient.
- There may be a meeting of all the professionals involved with the case to plan future care. If you wish to be involved in this meeting, advise the head nurse as soon as possible.
- Before the patient returns home, connect with the home care case co-ordinator and the individual's doctor.

PERSONAL CARE HOMES AND OTHER ALTERNATIVES

If care within the home is no longer a safe and viable option, it may be time to consider other options such as a personal care home (PCH), supportive housing or another community alternative. Discuss the options with the Home Care Case Co-ordinator. Whatever the choice, this will likely be a difficult transition for the care recipient. Start slowly and involve the individual in any discussions and decisions.

Application for placement in a PCH or supportive housing must be made through your home care case co-ordinator. A panel of professionals reviews the total application package, including a form from the doctor, and notifies the applicant and others identified of the decision.

Residents of a PCH pay a daily residential charge based on their previous tax assessment from Revenue Canada. In addition to meeting the criteria for care, the applicant must also meet the Manitoba residency criteria.

Expect mixed emotions. Those involved in your caregiving situation may feel both relief and sadness about the shift in caregiving responsibility that results from placement.

CAREGIVER RESOURCE LIST

PROVINCIAL GOVERNMENT RESOURCES

At Your Service Manitoba

In Winnipeg 945-3744

Toll-free 1-866-626-4862

Manitoba Seniors and Healthy Aging Secretariat

In Winnipeg 945-6565

Toll-free 1-800-665-6565

www.gov.mb.ca/sd

CAREGIVER RESOURCE LIST

SOME COMMUNITY RESOURCES

Age & Opportunity
in Winnipeg 956-6440

Creative Retirement Manitoba
in Winnipeg 949-2565

CONTACT Community Information
in Winnipeg 287-8827

La Fédération des aînés
franco-manitobains inc.
in Winnipeg 235-0670
1-800-665-4443

Alzheimer Society of Manitoba
Helpline: 1-800-378-6699

CAREGIVER RESOURCE LIST

Support Services to Seniors Program
Community Resource Councils (CRC)
For the nearest CRC, call the Seniors Information Line:
in Winnipeg at 945-6565 or
Toll-free 1-800-665-6565

Manitoba Society of Seniors
in Winnipeg 942-3147
or Toll-free 1-800-561-6767

COMMON QUESTIONS

"How do I know when my family member can no longer live safely at home?"

The person you are caring for may resist change. Respecting and recognizing that these changes will be difficult for the care recipient will help. Start slowly and involve him/her in any discussions and decisions. Listen without judging and reassure him/her that any new services will make them safer.

"I don't like the aide/volunteer/nurse/ companion who has been assigned to us. Am I stuck?"

You are not stuck. Discuss any concerns you may have with the person who has been assigned to assist with your situation. If you feel that your concerns are not satisfactorily resolved, call the home care co-ordinator or the agency/organization and speak with the social worker or supervisor. Explain your concerns and ask for suggestions. You can ask for a different aide if you feel it's needed. Personality conflicts are not uncommon and it is most helpful to find an aide that best meets the needs of the person you're caring for and your own needs.

COMMON QUESTIONS

"What is respite care?"

Respite care refers to the services provided to a caregiver so he or she can take a break from the caregiving responsibilities. Respite care can be offered through formal organizations or through short-term placement in a nursing home for the care recipient while the caregiver takes a break.

Respite care should be used regularly, so you can become more familiar with the respite staff and confident in the care that is being provided. Then you can relax and enjoy your break knowing you can trust the relief staff or volunteer to provide good care in your absence.

"How can I get help from other family members?"

Recognize that people are caregivers in different ways. Be specific in your requests. If your family refuses your requests for help, accept it and look to your community for help and support.

COMMON QUESTIONS

"Who can I count on for help?"

Ask for help and keep an open mind about what services and organizations can help. Listen to the suggestions of the person in your care.

"How do I fulfil my caregiving responsibilities and also take care of myself?"

Take time for yourself on a daily, weekly, monthly and yearly basis. Taking regular breaks allows you to cope with the stress and responsibilities of caregiving, otherwise the situation can become unbearable and affect the quality of your care.

COMMON QUESTIONS

"I don't believe the nursing home staff provides quality care. What can I do?"

You can start by addressing your concerns with the charge nurse or the administrator at the care home. Explain what your frustrations are, ask what they can do to improve the situation and ask when you can expect to see some changes. Follow up with your contacts at the care home on a regular basis. Personal care homes hold care conference meeting where family members can attend and discuss their concerns.

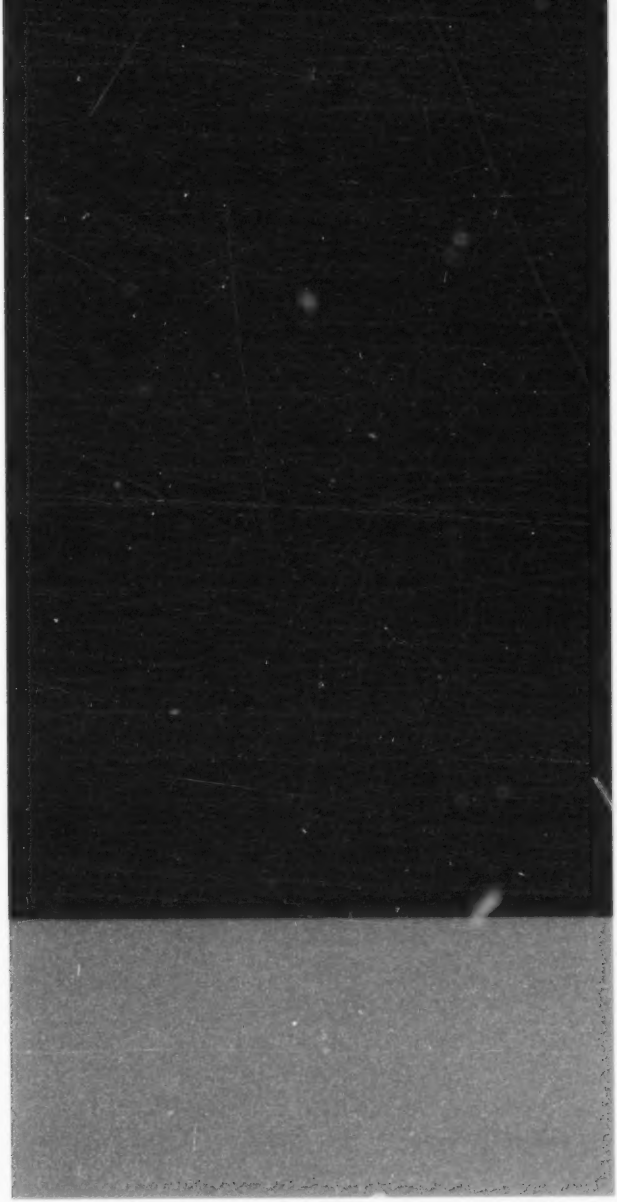
If you do not feel your concerns are being addressed adequately, contact the **Long Term Care Concerns Complaints Line at 945-4840 or Toll free 1-888-871-6276** or your local Regional Health Authority.

CONCLUSION

The job of caregiver will likely be one of the most important and demanding jobs you will ever have. In spite of the difficulties and frustrations, it can be a highly rewarding experience.

This guide provides information and advice that will help you cope more effectively in your caregiving role. Remember that aging is a fact of life. As time passes, we all have to adapt to the changes life brings. Your experiences as a caregiver may ultimately be a positive one.

NOTES



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